

FROM TRANSACTIONAL TO TRULY COLLABORATIVE

Improving Relationships Between Industry and Patient Organisations

Patient engagement in research is well established in the UK. A significant number of Patient Organisations (POs) in the UK involve people affected by health conditions in their research funding programmes and many support research teams to work with their patient communities to prioritise, design, deliver and disseminate research.

Patient engagement in research led by pharmaceutical companies is less consistent and, although this is changing, there is much work to do to understand how pharmaceutical and medtech companies are working together with patient, carers, family members and/or POs. This project aimed to provide clarity about how partnership working is being done across the medicines development process, and how this could develop in future. It hopes to help with planning and to encourage improved working practices.

The first step of the project was to conduct a review of literature. This revealed a lack of information about current working partnerships, focussing instead on standards of collaboration, aspirations, and case studies. This was followed up with a survey of pharmaceutical companies which received 52 responses from people working in a variety of roles and departments. Finally, a virtual workshop brought together a range of stakeholders to explore the survey results and develop recommendations.

Partner organisations



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



RESEARCH VERSUS ARTHRITIS

Key findings

- Our survey found that within companies, the functions that most commonly engage with patients and POs are Medical Affairs, Research and Development, and Corporate Affairs.
- Pharmaceutical companies reported that working with patients and POs was beneficial, especially in helping them to gain a better understanding of patients' experiences and unmet needs; in raising awareness and motivating staff; improving knowledge of healthcare delivery; developing more relevant outcome measures; and in informing strategic aims and direction. It was reported to have a significant impact on their work and on company decisions and direction.
- Patients and POs were involved throughout the medicines development process, but most commonly in the clinical research phase.
- Nearly two thirds of survey respondents said that they plan to increase their work with patients and POs in the UK over the next two years – aiming for long-term relationships based on partnership and co-creation. Over half were looking to run projects to better understand patient experience and need.
- Pharmaceutical representatives felt the most important role that POs could play is to sit alongside patients and carers to represent a range of experiences, as well as supporting the planning, management & delivery of engagement activities.
- Currently, varying interpretations and perceptions of risk from the ABPI Code of Practice in pharmaceutical companies can often block patient engagement activities, coupled with POs' limited understanding of the Code. Complex contracts are a significant barrier, as patients, carers, and POs often do not have access to legal advice.
- Early engagement leads to greater benefits, however the multiple entry points in pharmaceutical companies, complexity of global vs national engagement, internal communications, and POs capacity present barriers to this.

Recommendations

Companies and POs



Develop and support personal relationships



Build an understanding of each other



Develop overarching strategic frameworks

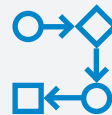
Companies



Engage with patients and POs earlier



Clearly communicate contact person



Improve standard operating procedures (SOPs) and infrastructure



Build on template contracts

Patient Organisations



Build an understanding of the Codes of Conduct



Develop your parameters for an effective partnership